CHAPTER 4

MAKING SENSE OF PARENTHOOD AND PERSONHOOD

Introduction
The notions of parenting and caregiving are culturally diverse. It implies that the socio-cultural context can shape the nature of caregiving. The birth of a child with disability is considered as an important occasion in which parents engage in a meaning making process in an attempt to make sense of their parenthood (Rapp & Ginsberb, 2001). This chapter examines how parents make sense of their parenthood vis-à-vis personhood of their child with disability. This chapter further discusses in what ways parents accept and resist these constructions. By drawing up on the parental accounts, this chapter explicates how socio-cultural contexts shape the parental experiences of caregiving. The narratives from this study indicate that parents have to raise their children with disability in a socio-cultural context which assign a ‘diminished personhood’ to their children. It affects the sense of parenthood and the meaning that parents give to their caregiving.

The first part of this chapter introduces the idea of “diminished personhood” and “diminished parenthood”. The discussion illustrates how the notion of diminished personhood of children with developmental disability is contingent upon social, cultural, medical and legal practices. It further illuminates how the status of diminished personhood of children with disability negates the entitlement to care. The subsequent part of this chapter discusses how parents make sense and interpret their parenthood in the course of caregiving to a child with diminished personhood. The final part of the chapter presents the meaning that parents attach to their caregiving to an adolescent with disability.

The Context of Caregiving: Contested Personhood and Parenthood

The essential idea of personhood is that human beings have a higher moral status as they possess a distinct set of ‘cognitive capacities’ such as self consciousness, rationality, autonomy, and capacity to communicate with others through language (Beauchamp,
The possessions of these ‘cognitive capacities’ are necessary to be treated as a person. In order to make claim for higher social, legal, and moral status as compared to non-human animals, individuals in a society are expected to possess these cognitive capacities (Wasserman, Asch, Blustein, & Putnam, 2013).

The status of full personhood is often reserved to adults with a ‘sound mind’. The assumption is that only adult members of the society possess the ‘cognitive capacities’ to engage in a social and legal contract. It is assumed that children do not, per se, possess full personhood but they have the potential to achieve full personhood or they are in a process of achieving full personhood. Thus, they are entitled to a set of inalienable rights.

When children enter adolescence, they may experiment and exert their ‘cognitive capacities’ such as autonomy and agency. Moreover, adolescence is considered a transition period in which children are likely to make their initial assertions of their personhood. Parents are likely to acknowledge and accommodate the efforts of the child to exert their ‘cognitive capacities’. The discussion presented here will illuminate how parents interpret the status of personhood in adolescents with developmental disabilities and how they make sense of their parenthood.

People with Developmental Disabilities and Diminished Personhood

The people with developmental disabilities are often kept at the margins of the moral personhood as they presumably possess a ‘diminished personhood’. The assumption is that neither do they possess the set of ‘cognitive capacities’ that are essential to the entitlement of personhood, nor do they have the potential to achieve these ‘cognitive capacities’ in long run.

In an attempt to disentangle the idea of personhood, Singer (2010), draws a comparison of the IQ status of people with profound developmental disability with a few non human species such as Great apes, dogs, and Gray parrots. His exposition challenges the personhood in people with severe developmental disability who apparently have lesser reasoning ability or IQ in comparison to some non human species. Thus, he argues that their moral and legal entitlement to care is questionable.
The notion of ‘diminished personhood’ in people with disabilities has many implications. It may justify the denial of moral and legal entitlement to care. Moreover, it normalizes the desirability of death in the case of people with profound disability. For instance, McMahan (1996) outlines a similar line of argument in his work on ‘the ethics of exclusion’ which in many ways naturalizes the early death of people with disability. Such views also emerged in the narratives of a few parents in the study. For instance, while interviewing Santhosh, father of a 17 year old boy with Autism, the researcher came across the following narrative.

_Once he consumed one cap of pesticide [Intrial Roger is heavy poisonous material used as Soya bean pesticide]. He did not die. He survived without much problem. It seems his body is immune to such heavy poison. He became unconscious for half an hour. Then he got up and started playing. I was away from the village for daily wage work. No one from the home informed me about it till I returned the home. When my wife came to know about it, they fed him salt water so as to vomit the poisonous content. But he did not vomit. He survived somehow._

_Santhosh, father of a 17 year old son with Autism.doc.18.17_

Although, Santhosh was hesitant to verbalize his indifference to this episode, his neighbour who was present there made the following comment which in many ways reflects the assumption for early death of a child with disability.

_He is not to going to die easily... Even the worst mad dog will not bite him (‘kithhi pisadlali kuthra asso theala chavanar nahi kuva kiti hi marka bail asso thyala marnar nahi’)_

_Field note dated 5-12-2014.doc.37.8_

The expression from the onlooker that ‘he will not die easily’ can be inferred as an attempt to normalize the early death of child with disability. The subsequent narrative from the onlooker was affirming the view that people with disability are not worthy enough to lead a meaningful life. Thus, an early death of the child would be better for their parents.

The death of a child with disability is interpreted something close to what Scheper-Hughes (1993) narrated as a ‘death without weeping’. The researcher also came across another parent who lost his daughter with disability during the field work period. While
reflecting on the death he said ‘it is better she died’. He said it with a sense of relief. The indifference to the death of his daughter was evident in his narrative.

Scholars like Kittay (2010) warns about the practical implications of ‘the ethics of exclusion’ proposed by McMahan. When a society confers a diminished status to some individuals and groups, it may result in discrimination, rejection, neglect, abandonment, and even killing. Research studies have shown that in some societies children born with congenital disabilities have been treated as non-human being such as spirits and snakes (Schepker-Hughes, 1993; Dettwyler 2013; Weiss, 1997; Gammeltoft, 2008). These studies illustrate how some societies negate the entitlement of people with disabilities to care on the account of diminished personhood. In other words, the notion of diminished personhood can result in dehumanizing the lives of people with disability.

On many occasions during the fieldwork, the researcher noticed the disposition of the parents, extended family members, and community members to draw parallel between the life of adolescents with profound disability with non-human species from the animal world like dogs, snakes, and cows. For instance, Nana, father of a child with Intellectual disability, described the birth of a child with disability as ‘birth of a poisonous snake’. The displeasure of accepting a child with diminished status is noticed in the caregiving description of Lathifa, mother of an adolescent girl with intellectual disability, who shared that ‘If God gave me a snake inside my womb, I have to accept it’. The intolerance towards birth of child with disability is surfaced in the caregiving descriptions of Rehana, mother of an adolescent girl with Cerebral Palsy, who shared that her father-in-law often advises her ‘to abandon the child in some Masjid’. Like Rehana, a few mothers in the study narrated incidents that illuminate the intolerance of family and community members towards the birth of a child with disability. The expressions that are often used to project the worth and dignity of the individual with disability reflect that adolescents with developmental disability have a ‘diminished personhood’.

The following description about the everyday life of a child with profound disability by an extended family member renders an understanding about how the status of personhood
is ascribed in a village setting. The description, in many ways, reflects how for some people with developmental disability personhood is highly ambiguous or absent. As a participant observes;

*This boy moves around the village just like a disabled dog. He drinks water from drainage and he eats waste food. Nobody takes care of him. When there is rain I ask him to go to the house. But he does not understand it. He aimlessly moves around the village or nearby village... What can one do with such a child? He is grown up. But he wanders around the village naked. There are other three grown up girls in the family. But he does not understand it.*

*Kalavathi, grandmother of 18 year old boy with Cerebral Palsy.doc.37.5*

The metaphor of a ‘disabled dog’ indicates that a sub-human personhood is attributed to a person with severe developmental disability as he does not possess any attributes of personhood such as self consciousness, capacity to communicate, and comprehend. The subsequent narrative about the everyday life of the boy in this case conveys that the life of persons with disability is not worthy enough to pursue.

Similarly, while interviewing a parent of child with Autism, the researcher encountered the following remarks from one onlooker who was present there. It illuminates the diminished personhood of an individual with disability.

*This boy does not have any sense and brain. He doesn’t know how to eat and he doesn’t know where to shit. What is the benefit of caring this child? It is better to rear a cow. They will get some benefits from it...Hariba’s son (another villager) had similar problems. He spent lot of money for the treatment. But there was no improvement and the child died eventually. Vishal also has same problem and he will die at a very young stage.*

*Field note dated 5-12-2014.doc.37.5*

One of the common notions about the life and personhood of a child with disability is that they will lead an unproductive life and may not contribute to family and to the larger society. The child with disability is rarely seen as a person contributing to the family life. Thus, the act of caregiving to a child with disability is seldom acknowledged and appreciated.

The experiences of the parents indicate that there is a general devaluation, denial, and rejection of the personhood of their child with developmental disability by the members
in the family and community. Though the content, meaning, and tone in which the
devaluing remarks were made by the actors in the social institutions varied, it conveyed
the message to the parents that their child has diminished personhood. Let us now look at
how the status of ‘diminished personhood’ in children affects the status of parenthood.

**Parents of Children with Disability and Diminished Parenthood**
The diminished status of personhood in the child with disability has implication for the
identity of parents and their parenthood status. The narratives of many mothers in the
study indicate that they experience ambiguous motherhood when their first child was
born with a disability. The ideal motherhood is reserved for women who give birth to the
so called ‘perfect baby’.

In patriarchal family settings, a healthy male child is idealized as a ‘perfect baby’. The
status of parenthood remains ambiguous when parents fail to meet the expectation of a
‘perfect baby’. This can be noticed from the following narratives from Shalini, mother of
a boy with intellectual disability.

> **My relatives keep on telling me that you are lucky to have a male child but
unlucky to have a child with disability. I feel bad when I hear such comments. I
consulted many traditional healers and religious preachers... But it was waste of
time and energy. I think it is my destiny. What can I do? I cannot change it.**

*Shalini, mother of a 13 year old boy with intellectual disability.doc.25.2*

Sachin, father of a girl child with multiple disabilities, shared his expectations about a
‘perfect baby’ in following words

> **I was expecting a male child. My first daughter was born with serious
disability...I treat her as my son. Later we got four girl children... Our entire
family is waiting to see our sixth child. The whole family is expecting for a male
child...We need a male child to look after our land and agriculture... Otherwise, I
don’t see much value in the wealth I have.**

*Sachin, father of a 14 year old girl with multiple disabilities.doc.50.1*

Although Sachin belongs to the dominant caste community and is relatively rich with 125
acres of agricultural land, he feels that the status of his parenthood depends on birth of
male child who can inherit family wealth. Similarly, Sagar, father of an adolescent boy
with intellectual disability narrated how his parenthood got diminished after the birth of a
child with disability and how he regained the status of parenthood after the birth of his second child.

*After seeing my first child, I used to think that what is point in accumulating so much wealth in life...Sometimes I think that saving money for the future is a futile thing. Who is going to inherit my wealth? I don’t think my child will be able to take any benefit of my wealth. ... When I am not sure about the benefit of my wealth to my child, why should I work and earn more money?... Parents work hard to earn some money so that their child will have prosperous life. But my child is not going to get any benefit from my wealth...My second child was born after five years. I had tension about him. I am happy to see that I have a normal healthy son. When I think about my second child, I feel that I have some purpose in my life. I also feel that at least I have one child who will take the benefit from my wealth.*

*Sagar, father of 18 year old boy with Intellectual Disability.doc.17.11*

Like Sachin, Sagar also belongs to the dominant caste community in the village and is relatively rich with 80 acres of agricultural land. As we see in both cases, the notion of ideal parenthood is attached to the ability of parents to reproduce a healthy male child. It can be interpreted that their notion of personhood in children with disabilities and the status of parenthood are inextricably linked to structures of patriarchy. The patriarchal belief that only a healthy male child can inherit the property of their parents’ can discount the personhood of children with developmental disabilities, and it can diminish the status of parenthood. The status of parenthood becomes ambiguous or parents may experience a tainted parenthood till the birth of healthy male child.

In order to gain the status of ideal parenthood the parents are expected to try for more children. For instance, Reshma, mother of an 18 year old boy with Cerebral Palsy, shared how she was persuaded to think about a second child as the family was not willing to accept her first child.

*I was not keen to have another child as I was planning to devote much time for my son. But my mother was urging me to have another child. She used to remind me that I should not expect much from my son. You cannot count him as family member who can do something for the family...He may not be able to give company to his younger sisters. His existence is only a matter of a number.*

*Reshma, mother of 18 year old boy with Cerebral Palsy.doc.32.5*
The above narrative also indicates that diminished personhood has implications not only for the lives of children with disability but for their parents as well. Some parents in the present study reported that they are enticed to subscribe to a feeling of what Landsman (2008), describes as “It’s like You Don’t Have a Baby”(p.50). Ghai & Johri (2008) note in their study, it is not easy for parents to choose to give birth to a child with disability and to challenge the dominant constructions of both parenthood and childhood in a society which constantly discount and discredit the worth of people with disability.

Moreover, giving birth to a child with disability confers an inferior social status to the parents in their kinship relations. The parents shared many incidents in which they were forced to be invisible in social and family gatherings. The appearance of the child with disability and their parents in social or family functions is treated as a serious blot on the family status and to the auspicious nature of family functions. This dimension will be discussed in the chapter on stigma.

The narratives of the parents indicate that the diminished personhood status of the child with disability in the society limits the choices for education, peer socialization, and medical care of the child. Parents narrated many incidents where the utility of education and health care for their child with debilitating condition has been questioned by lay people as well as professionals such as school teachers and medical care professionals. This will be discussed in detail in chapter 5 on caregiving engagement of parents.

**Differential Experience of Diminished Parenthood**

One of the intriguing observations that stem from this study is that the experience of diminished parenthood is not uniformly distributed among the mothers and fathers. Mostly mothers have been ascribed with the status of diminished motherhood. It partly stems from the belief that mothers are responsible for the birth of a child with disability.

As we noticed above, a failure to give birth to a healthy male child is considered as failed parenthood. To achieve the status of ideal parenthood, men are allowed to remarry. For instance, Pankaj, father of 17 year old adolescent boy with Autistic Spectrum Disorder disclosed that the failure of his first wife to give birth to a healthy child compelled him to marry again within a short interval of less than three years.
After diagnosis, doctor informed that my son is mentally retarded. All of our relatives encouraged us to have a second child. But we had no choice when I noticed some problem with menstrual cycle of my first wife... Since, our first child is mentally retarded and my wife has problem, I decided to have a second marriage. My first wife gave permission to that. Later on we consulted a doctor in Barshi. When he came to know about my second marriage, he scolded me. After the diagnosis, the doctor assured that my first wife will have a regular menstrual cycle, and he suggested some treatment...Later she gave birth to a healthy girl child.

Pankaj, father of a 14 year old boy with Autism.doc.9.3

It indicates that when the first child is born with disabilities there is some kind of social sanction for second marriage even though there is no legal sanction. However, the social sanction for second marriage is often restricted to fathers. Like in the case of Pankaj, the researcher came across a couple of other families who shared similar views. It is more apparent in the narratives of Shobha, mother of a 17 year old boy with Cerebral palsy.

Whenever, I get invitation to attend marriage or any other kind of function, I avoid such gatherings. When I say no to such invitations, my relatives make comments that my child is not going to bring pride to the family. They often discourage me. Even his father is now not much keen to take care of him much. Now there are people who have started advising my husband to marry another woman. They often remind him that his child is not going to support him in the future...He is more than 50 years old. When will he have his next child? Who will take care of this child? I am really worried.

Shobha, mother of a 17 year old boy with Cerebral Palsy.doc.33.3

The experience of Shobha illustrates how the status of motherhood gets diminished and the gender inequality render a differential experience to father and mother. She waited for almost 14 years to have her first child. She used to be blamed for infertility. Now she faces blame for giving birth to a child with disability and her motherhood becomes tainted. Mothers often face the stigma of being a bad parent. This aspect will be discussed in next chapter on caregiving stigma where stigma in caregiving is discussed.

The parental construction of caregiving must be examined against the backdrop of a socio-cultural milieu which attributes a diminished personhood to a child with disability and a diminished parenthood to a parent who take up the role of a primary caregiver. As
mentioned earlier, the notion of parenthood and personhood is socially contingent. Let us look at how the notion of ‘diminished personhood’ and ‘parenthood’ evolves from the existing social, cultural, legal and medical practices in India.

**Social Construction of Diminished Personhood**

It seems the conception of personhood and parenthood are not given rather it is constructed over a period of time. Gammeltoft (2008) argues that “personhood is culturally variable, socially contingent, and historically shifting” (p.839). He further argues that in any given context, the notion of person is ‘made up’ and it is likely to change. It is plausible that parents construct the notion of diminished personhood of their child from the cultural, medical, and legal practices and prescriptions. We will look at how the cultural, medical, legal, and social practices in India which construct the notion of diminished personhood status to people with disability and how it shapes the rights and entitlement of people with disabilities for care.

**Prenatal Diagnosis**

The routine prenatal diagnosis can shape the parental perception about what kind of child they must expect and accept. In many ways the practice of prenatal diagnosis crystallizes and consolidates the dominant notion of personhood.

In an attempt to persuade the parents to abort foetus with potential anomalies, the life of people with disability is often portrayed negatively. The opinions of medical care professionals and the practice of prenatal diagnosis have a role in discounting the worth of people with disability. It has the power of vetting and vetoing the personhood status in people with disability.

The parents in the study who had access to prenatal diagnosis shared that medical doctors persuaded them to abort their child when some anomalies with foetus was noticed. However, some of them choose to give birth to a child with disability. The idea of abortion goes against their religious beliefs. For instance, Latifa, mother of two children with multiple disabilities shared that she was in a dilemma when the doctors asked her to abort the child.
When I was expecting Mousin, I had fever and cold. We consulted a doctor. He told us about the possibility of birth defects. ... He told us that it is better to abort the child...But we did not go for it.

Lathifa, mother of two children aged 18 and12, with Multiple Disabilities.doc.30.1

Like Lathifa, a few other parents had prior knowledge about birth defects of their child with disability during the pregnancy period but decided not to abort their child with disability. Indeed, their choice of accepting a child with disability imposes additional parental blame on them. Asim, father of an adolescent girl child with disability, shared the choice he has made and the reactions of his extended family members in the following words.

I was informed about the possibility of birth defects with my first child. The doctor who noticed it during the routine pregnancy check up suggested us to abort the child. I got tensed when I got to know from the doctor. We decided to consult another doctor. We met a doctor. He confirmed the views of previous doctor and advised as to go for abortion. I was not happy with his suggestion. I told him that I will discuss it with my wife and other family members. I was in a dilemma. I was confronted with the question that how I can think of taking life of my first expected child? I felt it is a crime on my part to take the life of my first expected child. We decided to accept our first child even if he or she takes birth with some disability. I discussed with my family members. We felt it is a sin to kill a child even before this child take birth. It was collective decision to continue with the pregnancy of my wife. People often blame me for the decision that I took against the abortion of my child [Emphasis added].

Asim, father of a 12 year-old daughter with Cerebral Palsy.doc.36.11

While parents like Lathifa and Asim shared the dilemma that they had faced in aborting their child on religious ground, a few other parents shared their disappointment for not aborting their child. They said the doctors did not advise them to abort their child during pregnancy. Although Reshma, mother of an adolescent with Cerebral Palsy, appeared to be confident and optimistic about their caregiving, she shared her disappointment with doctors who concealed the birth defects of the foetus and did not offer a choice for aborting the foetus.

At the beginning of pregnancy we consulted a doctor. After the scanning, she told us that there is more water [referring to amniotic fluid]. But she did not tell us what to do? She did not share about the problems that may arise out of it. She did
not reveal risk associated with the growth of the child. She did not advise about
the options for the abortion in complex situation. She did not provide any advice.
We were also completely ignorant about it.

Resham, mother of a 18 year old son with Cerebral Palsy.doc.32.9

The practice of prenatal diagnosis idealizes certain human bodies. It conveys the message
to the parents about what kind of human bodies are preferable. As we noted earlier, the
intolerance to the birth of child with disability was evident in the narratives of many
parents. The failure of the parents to take the advantage of reproductive technologies and
to abort foetus with anomalies has invited criticism both from the extended family
members and medical doctors. This aspect will be further discussed in the chapter on
stigma and parental blame.

Some parents in the study talked about the social pressure that they faced to undergo
prenatal diagnosis when they were expecting their second child. For instance, Sagar,
father of a child with intellectual disability, shared that all his family members were upset
with the birth of a child with disability in their family. It compelled him to seek
counselling in many metro cities when they planned to have a second child.

I was tensed when we were expecting our second child. We consulted a doctor
during the pregnancy of our second child. We had undergone various tests ...
During the entire pregnancy period we were tensed. Just before the delivery, my
wife was too tensed and emotionally disturbed.

Sagar, father of 18 year old boy with Intellectual Disability.17.11

Similarly, Meenakshi, mother of 15 year old girl with Cerebral Palsy shared that

We had a consultation with doctor before the pregnancy of our second child... We
wanted to ensure that we will have a healthy and normal child.

Meenakshi, mother of 15 year old girl with Cerebral Palsy.doc.68.6

It seems that the introduction of reproductive technologies has changed the notion of
personhood. It has contributed to what Landsman (2008) called “the construction of
perfect babies” which in turn devalued the worth of children born with disabilities. Many
participants in the study shared the pressure they faced to undergo regular pre-natal
diagnosis from members in their immediate and extended family. The pressure on parents
to undergo prenatal diagnosis and the practice of intensive bodily surveillance during the
pregnancy can be interpreted as a manifestation of society’s intolerance to weak human bodies.

**Legal Framework**

Looking at the existing legal frameworks related to people with psychosocial disabilities in India, Davar (2012) notes that people with the unsound mind are treated as “non-persons”. She argues that the dominant medico-legal discourse exerts a powerful force in shaping the status of personhood in people with disabilities. The dominant conception of personhood has implications for the nature of care that people with psychosocial disabilities are entitled from their family, community, and institutional care systems.

The negation of personhood in people with disability can be gleaned from the existing medico-legal frameworks in India which grant legal sanction to the medical termination of foetus with potential anomalies.

**Guardianship and the National Trust Act, 1999**

Legal institutions and its practices can perpetuate the notion of diminished personhood in people with intellectual disabilities. The idea of guardianship entailed in the National Trust Act 1999 is an example to illustrate how the legal institutions can undermine the autonomy and agency in person with developmental disabilities. The idea of guardianship can reinforce the notion of diminished personhood. The concept of guardianship is built on the presumption that people with developmental disability do not possess agency, free-will, autonomy, and rationality to manage their own day to day affairs. Hence they require guardianship. In the other words, the idea of guardianship undermines the cognitive capacities of people with developmental disability. Thereby the status of personhood in people with disability gets diminished.

While drafting The Disability Rights Act 2016, the clause on legal capacity has generated heated debates (Ghosh, 2016). The idea of legal capacity presupposes that people with disability must have the right to exercise their autonomy and agency in deciding matters related to their own lives. The assertion for the legal capacity in many ways is an assertion for the personhood. It may acknowledge the possession of ‘rationality’ and ‘autonomy’ which are necessary to affirm the personhood in people with disability.
While lobbying for the rights of people to exercise their own will, the organization of people with ‘dominant disability’ advocated for the clause on legal capacity (Ghosh, 2016). The argument for legal capacity is made on the apprehension that the notion of guardianship negates the personhood. The operationalization of guardianship may reinforce the view that people with disability do not possess the ‘cognitive capacities’ that are necessary for them to make a claim for personhood.

On the other hand, the organizations of parents having children with developmental disabilities opposed the clause on legal capacity. They perceived that their wards would never be in a position to exert their own will. It may generate avenues for the exploitation in which people with vested interests may try to appropriate the property and wealth of people with developmental disabilities (Ghosh, 2016). It can be noted that the legal construction of personhood ingrained in the legal practices can be empowering as well as disempowering. The notion of legal capacity can affirm the personhood status. At the same time the notion of Guardianship can diminish the personhood of people with disabilities. The possibilities for resolving the disagreement is not easy.

The parents in the study hold the view that their children are unlikely to acquire sufficient cognitive to make life choices. It implies that their children do not possess the faculties of ‘autonomy’ and ‘rational thinking’ which are assumed to be essential to lead an adult life. Many of the parents anticipate that their child will lead a miserable life after their death. It was one of the central concerns that repeatedly echoed in the narratives of many parents. Some parents, who have children with severe disability, disclosed that they prefer an early death of their child. Suvarna, mother of an 18 year old girl with Intellectual Disability believes that her daughter possesses limited cognitive abilities to lead an adult life. She expressed her concern in following words.

When I am alive, I attend her basic needs. But after me, who will take care of her? ... I will take care of her till my death. The day I will die, others have to burn her along with my dead body

Suvarna, mother of 18 year old girl with Intellectual Disability.

Like Suvarna, many parents in the study expressed similar concern. Although a few parents discussed about their plan to earmark their properties and saving for their child
with disabilities, they have the apprehension that it will be appropriated by people with vested interest. Arthik, father of an 18 year old child with intellectual disability shared that ‘considering his mental capacity, it is not a viable idea to deposit some money in his account in a bank’. While parents make an appeal for the guardianship to their child in the absence of dependable second generation of caregiver, it reinforces the notion of diminished personhood in their child with disability.

Cultural Conception of Disability and Tainted Parenthood

The notion of ‘diminished personhood and parenthood’ stems from the various cultural constructions of disabilities. In the absence of sufficient explanation for cause of disability, parents as well as community may subscribe to various explanations available in cultural repertoire. Previous studies in India and elsewhere give evidence for the prevalent practice of interpreting the birth of a child with disability in cosmological terms using notion of *karma* (Dalal & Pande, 1999; Dalal, 2002; Gammeltoft, 2008; Gupta, 2011). These cultural explanations that many of the parents used to interpret the cause of disability are rooted in the religious doctrines, such as *Karma*, curse of Brahmin, outcome of cosmic factors, black magic and a few other cultural practices.

It is noted that in an attempt to interpret the cause of disability, both parents and the members in their community use various cultural explanations and interpretations. For instance, Arthik, father of an 18 year old boy with Intellectual Disability hold the belief that a deity of ‘*Kandubha*’ invaded in the body of his son and it resulted in seizures and convolutions. Rameshwar, father of an adolescent girl child Cerebral Palsy believes that the disability of his daughter is a consequence of a Brahmin’s curse. Surekha, mother of a 17 year old boy with Cerebral Palsy believes that the disability of her son is a result of black magic of some people in their neighborhood. Like Arthik, Rameshwar, and Surekha, many parents in the study cited various cultural explanations for the disability of their child. In a few cases, parents hold the belief that their children possess heavenly or spiritual power. We will come to this aspect at the end of this chapter.

The religious doctrine of *Karma* is one of the common cultural explanations used by the parents in the study. The notion of karma has different interpretation. The essential idea
of karma is that every action that we undertake has a moral consequence. It shapes the present existence and future life (Gmmeltoft, 2008). Karmic consequences stretch beyond individuals. It may have implication for the families and relatives. The disability of the child is often attributed to the moral breach by parents, usually in previous birth.

The parents in the study narrated numerous instances in which they encountered Karmic interpretation of disability so as to explain the cause of disability. Meenakshi, mother of a child with Cerebral Palsy, cited one such incident.

After seeing me and my daughter some aged women make comments, “Oh what happened to you and your child?... You got a child like this because you might have done some serious sin in your past birth. That’s why you got a child like this”.

Meenakshi, mother of 15 year old girl with Cerebral Palsy.doc.68.6

When disability is interpreted using the religious notion of Karma, the moral integrity of the person with disability and their parents will be subjected to question. Asim, father of a girl child with Cerebral Palsy narrated how his moral integrity is often doubted when people in his community interpret his daughter’s disability in Karmic terms

There are people who often tell me that I got a child like this because I did something wrong in the past. Even people who are close to me make such remarks. It hurts me a lot. I often tell them, I don’t know what kind of sin I have committed in the past. Only god knows about it. It is unfair to blame me. At least I must know what kind of crime I have committed in the past to justify the kind of punishment I am going through.

Asim, father of 12 year old girl with Cerebral Palsy.doc.42.11

Similarly, Mulla, father of two children with Multiple Disabilities, shared how people in his extended family cast aspersions on his moral integrity after the birth of two children with disabilities.

We don’t know what kind of sin that we have done in the past life. We don’t know the reason for getting a child with disability in our family. When we commit a small mistake or any small negligence happened from our side, they attribute it to our child’s disability.

Mulla, father of two children aged 18 and 12 year old with Multiple disabilities.12.28
Many parents in the study reported that the doctors who diagnosed their child seldom explained the reason for the disability of their child. In the absence of clear medical explanations about their child’s disability, parents are often compelled to accept explanations offered by others from the existing cultural repertoire.

It seems that the parents construe the meaning of personhood in their children with disability from the existing medical, legal, and cultural repertoire which assign a ‘diminished personhood’ status to people with disability. The parental construction of personhood in children with disabilities in the study needs to be interpreted considering the social, legal, and cultural context which denies and devalues the personhood in people with disabilities.

**Parental Interpretation Personhood of Children with Disability**
The narratives of the parents in the present study indicate that it is not necessary that parents stick to the culturally imposed views of absent personhood in their child with disability. In an attempt to restore the personhood, they construct alternative views about the worth of their child with disability. For instance, some parents in this study, who apparently held a positive image of their child with disability, shared that the birth of the child in their family brought some economic progress. They believe that the birth of a child with disability is a sign of incarnation of God. The presence of their children with disability in their family provides them a protective cover from wrath of the God. It was noticed that irrespective of religious backgrounds and the socio-economic status, some parents in this study hold such belief. For instance, Rasheed, father of a 13 year old girl with Cerebral Palsy, shared one of such practices.

*I think it is our destiny to have a child with disability. But I don’t regret about. After the birth this child, my economic condition improved a lot. The economic condition of my family was very poor during those days... But after the birth of Zeenat our economic condition improved. So I never felt, the treatment expenditure for Zeenat as loss or as an economic burden.... There are some people in our locality who believe that my daughter has some kind of heavenly power. They visit her and touch her feet when they are going to do something new or difficult thing. Some of them give her money. They tell us that my daughter is an incarnation of “Lakshmi”. They also tell us that unfortunate things will not happen in our family because of her presence. We also hold that belief. We attend*
her needs with utmost care. When people pass through our house, they greet her and touch her feet or wheelchair.

Rasheed, father of 13 year old girl with Cerebral Palsy.doc.51.1

Similarly, Mulla father of two children with Multiple Disabilities shared that he touches the feet of his children before he proceeds to his work. He considers his children as lucky children who brought prosperity to his family.

Sometimes they make special demands. That day I will have lot of customers in shop. So when I leave the house, I touch their feet and I spare time with them before leaving for the shop. In the evening I will bring some Somasa for them. I think they are my lucky children.

Mulla, father of two children aged 18 and 12 years with Multiple disabilities.doc.12.31

Similarly, Shanthabai, mother of an 18 year old boy with Intellectual Disability observes

My husband treats Anna as gift. He may scold and even beat other children. But he never scolded and shouted at Anna. Our family members believe that Anna is a gift from God and we are lucky to have a child like him. We became financially stable well off after the birth of Anna. (Theja payat Lakshmi aahe). My husband never made any casual remarks such as I am responsible for the birth of the child. He never accused me because I gave birth to a child with disability. He never shouted at me, never had a fight with me and never remained in tensed condition.

Shantabai, mother of an 18 year old boy with Intellectual Disability.doc.24.21

Chandu, father of a girl child with severe Cerebral Palsy and an educated government employee shared that he will ask his daughter to put some currency note whenever he purchases a new wallet. He believes that there is some divine power with his daughter and such ritual bring money and prosperity to his family. For some people such rituals are performed in a highly private space. For a few others like Rasheed such rituals become an accepted practice for the whole neighbourhood.

This parental construction of personhood in their child with disability can be interpreted as an attempt to present their child positively in a society which devalues the bodily difference of their child. It also shows that the parents may not subscribe to the prevailing cultural explanations given by others from the repository of cultural system. Rather they
may construct a set of counter narratives so as to attach a new meaning to their caregiving.

**Summary**

This chapter has explored how parents make sense of their parenthood vis-à-vis personhood of their children with disability in a caregiving context which devalue the worth a child with disability. The discussion on diminished personhood of children with disability highlighted how the classical notion of personhood grounded in the notion of ‘cognitive capacity’ accord a diminished personhood to people with developmental disabilities. It is further noted that the notion of diminished status is contingent upon medical, legal, and cultural practices that prevails in India. A closer examination of medical practices such as prenatal diagnosis, abortion laws, and legal clauses on legal capacity and guardianship construct the notion of diminished personhood of people with developmental disability. In other words it can be noted that the notion of diminished personhood is very much ingrained in the practices of medical care system, legal system and cultural system.

It is noted that parents experience a tainted parenthood when a child with disability takes birth in a family. It is further noted that society is intolerant to children whose bodies and cognitive capacities differs from expected attributes of ‘perfect baby’ i.e. a healthy male child. It is noted that the experience of tainted or diminished parenthood varies in terms of gender and socio-economic status of the parent. Mothers often experience a higher degree of diminished parenthood status. In spite of the awareness that they have been raising their disabled child in a social context which diminishes the personhood of their child and taint the parenthood, a strong sense of devotion and commitment was noticed in many parents especially among the mothers in the study.

Perpetual devaluation of a child with disability by the members of extended family and community discounts the worth of parental caregiving. The parental accounts of caregiving highlights that parents are expected to render their caregiving in a social context which devalues the personhood of a child with disability and diminishes the parenthood of the caregiver. This can distance parents from their caregiving responsibilities and it may eventually result in caregiving neglect, stigmatization,
discrimination and normalizing violence against people with developmental disability. We discuss in the coming chapters how the notion of diminished personhood limit the choice of children with disability to education, socialization, work, and other arenas of social life.

This chapter also highlights how parents resist and reconstruct the personhood in their child with disability. As Conklin & Mogan (1996) notes cultural construction of personhood are rarely shared invariably by all member of a community. As we see in this study, parents may evoke different interpretation to suit to different purpose. In an attempt to reaffirm the personhood of their child and to regain the status of parenthood, parents employ strategies such as attributing supernatural power to children with disability. Although it helps to attach a positive outlook towards their caregiving responsibilities, it can discredit the humanness in people with disability.

The observations from this study support the findings from previous studies. For instance, Mehrotra’s accounts of cultural construction of intellectual disability in a rural context indicates that such people are treated as “bawla or bhola (simple and innocent)” echoing a personhood of an individual with intellectual disability as something close to infants (as cited in Mehrotra, & Vaidya, 2008). She argues that adolescents with intellectual disability have an infantilized personhood status. In other words, they are rarely treated as a full person. The present study highlights that it is not necessarily the case when it comes to adolescent children with severe disability. While infants are assumed to have the potential to achieve the status of full person in the long run, it is believed that the children with profound disability do not have the capacity to achieve it in long run. This notion can have implication for the kind of care that they are entitled from family and the larger society.